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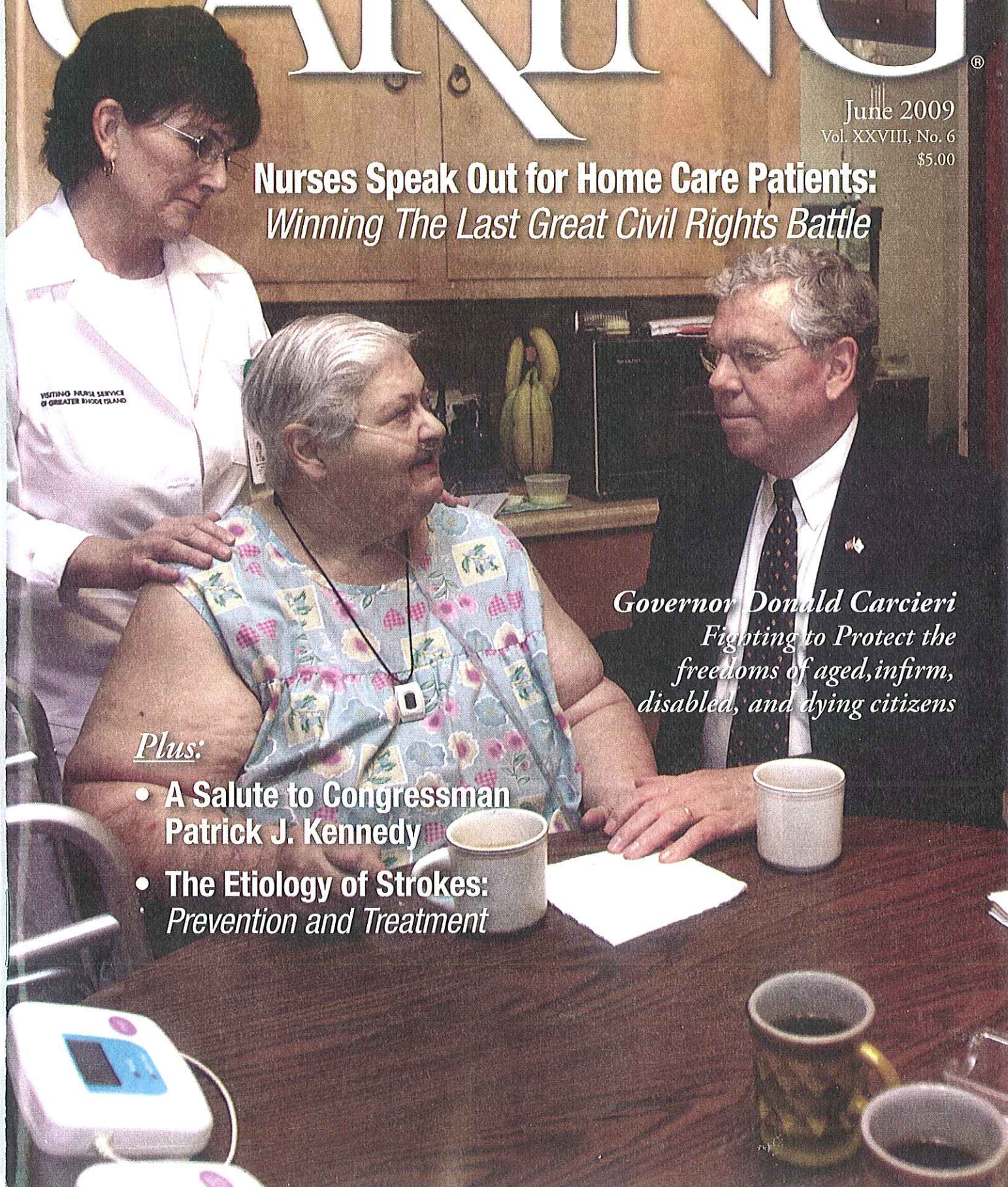
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Nurses Speak Out for Home Care Patients: *Winning The Last Great Civil Rights Battle*

*Governor Donald Carcieri
Fighting to Protect the
freedoms of aged, infirm,
disabled, and dying citizens*

Plus:

- **A Salute to Congressman Patrick J. Kennedy**
- **The Etiology of Strokes:**
Prevention and Treatment

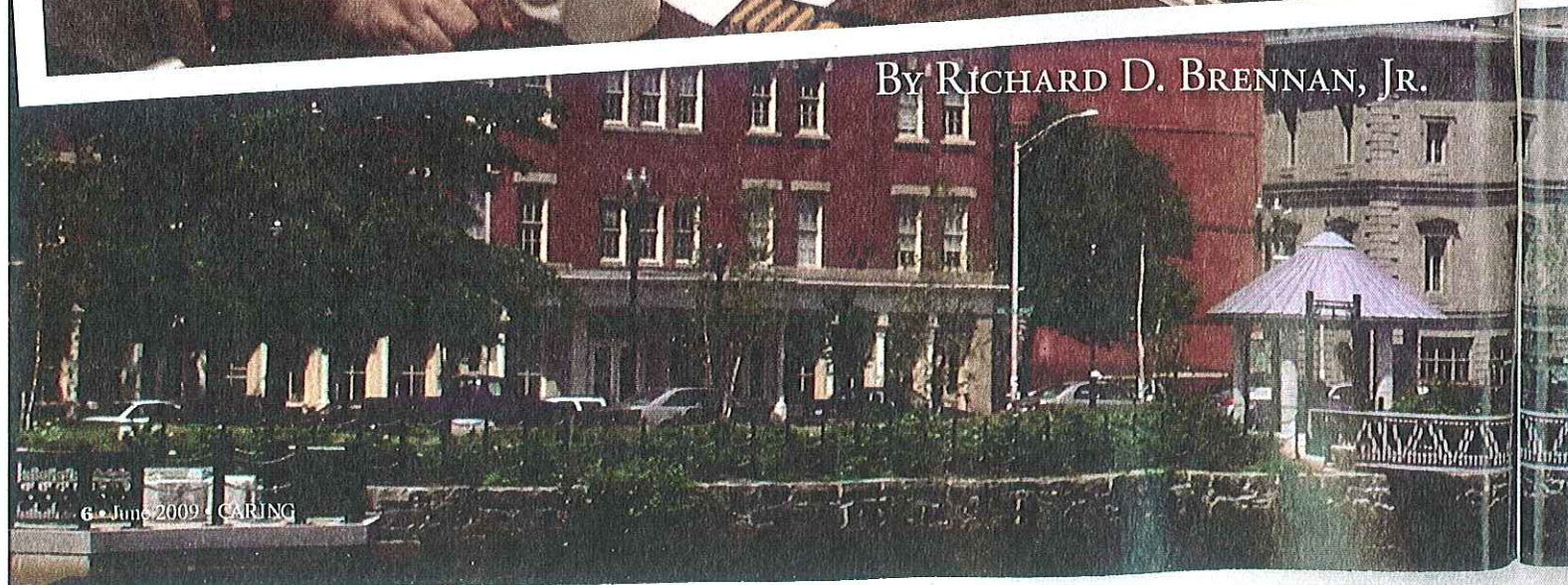


GOVERNOR DONALD CARCIERI

*Fights to Preserve the Rights
of Infirm and Disabled Citizens,
Champions Home Care*



BY RICHARD D. BRENNAN, JR.



Governor Donald Carcieri is a man of great intelligence, integrity, and firm convictions. From the time he was a young man, he always had his priorities in order: God, family, country, and Rhode Island. He was blessed to be the oldest of five children born to Marguerite and Nicola Carcieri, a beloved teacher and coach at the local high school in East Greenwich, Rhode Island.

From the time he was a lad, Governor Carcieri learned from his father the importance of education and of doing everything you can to make the world a better place. The Golden Rule was not a lofty abstract principle to him, but something that he and his family put into practice. He understood the importance of another commandment: "Honor Thy Mother and Thy Father that thine own days shall be long upon the earth." The values and lessons that he learned at his father's knee have served him well in later life and paved the way for his success.

Young Donald excelled in school. He was elected class president and student council president and was a star on the basketball, football, and baseball teams. But it was his stellar record in academics that earned him a scholarship to Brown University. He worked in construction and as crew on charter boats during the summer in order to supplement his income and help buy books. He graduated in 1965 with a degree in International Relations.

Immediately following graduation, Carcieri married his childhood sweetheart, Suzanne Owren, also of East Greenwich. Over the years their family grew to include four children and 14 grandchildren. With his first job he chose to honor his father and the community that had nurtured him by teaching high school. Serving others clearly is a family tradition.

After a few years, he was presented with the opportunity to be a bank executive, and he made the most of it. For 10 years he worked at the Old Stone Bank, reaching the position of executive vice president. His success was formidable, and he was on the ladder for advancement within the banking industry. But in 1981, he chose to leave it all behind and respond to his humanitarian instincts. He moved his family to Kingston, Jamaica, where he headed the West Indies Office of Catholic Relief Services. Carcieri again reveled in this opportunity to serve others and do good.



Above (top picture) Frank Ball, husband/caregiver, welcomes Gov. Donald Carcieri; (middle picture) Concetta Ball, wife/patient, with Linda McCormick, R.N., Gov. Carcieri and Frank Ball; and (bottom picture) Corinne Calise Russo, Director of Rhode Island's Dept. of Elderly Affairs meets Concetta Ball while Linda McCormick talks with NAHC's Rich Brennan.



Above (top picture) Elaine Stephens, CEO of the Visiting Nurse Service of Greater Rhode Island, with Concetta Ball and Linda McCormick; and (bottom picture) Concetta Ball shares a cup of coffee with Governor Carcieri and discusses her positive experiences with home care.

In 1983, Carcieri returned to Rhode Island, having accepted a position as president of Cookson America, a small start-up manufacturing company. In the space of 14 years, before retiring in 1997, Carcieri transformed the company, becoming CEO of Cookson and joint managing director of Cookson Group Worldwide. Under his leadership, the company had grown from a local concern with a few hundred people and \$30 million in sales to an international powerhouse with 12,000 employees and \$3 billion in sales.

In the years following his retirement, Carcieri again turned to humanitarian service. He and Suzanne raised money for, gave time, and personally supported numerous causes. In 2001, Rhode Island was racked by a severe financial crisis that made Carcieri begin to think about public service and running for governor. In April 2002, he announced that he was running for the Republican

nomination in this most Democratic state of the nation. Though he had never held public office, he won a contentious primary against an experienced opponent. Running on a platform of fiscal reform and renewed government integrity, he was elected the state's 57th governor on January 7, 2003. Delivering on most of his promises, Carcieri was reelected in 2006.

Having succeeded in restoring his state to a sound financial footing, Carcieri turned his attention to developing a state-wide economic development plan and improving the state's education system. Most recently, he has turned his hand to health care. In this connection, he focused his attention on better ways to care for the seven percent of Americans who suffer from multiple or chronic diseases and account for almost 50 percent of Rhode Island's health care costs. For Carcieri, who is known for his business acumen, it is really a very simple matter. (The conclusions below are gleaned from or implied in the interview that follows this introduction).

1. The major need in health care is help with managing chronic disease.
2. Chronic disease makes up the lion's share of health care costs.
3. The health care system was designed to help with acute care but starting in 1995, more people died of chronic diseases than of acute diseases.
4. The current system is biased toward institutional care, but what is needed is a system of home and community-based care.
5. The state Medicaid program, which makes up about one fourth of the state's budget, is disproportionately geared to institutional care; such expenditures need to be "rebalanced" with home care receiving preference.

A few months ago, Governor Carcieri won approval from the Department of Health & Human Services for a global waiver, which will allow him and his staff to rebuild Rhode Island's Medicaid program on a foundation of home and community-based care. I had the privilege of escorting the governor on a home care visit to meet 78-year-old Concetta Ball, who has suffered two major

strokes in the past three years. Nurses and therapists from the Visiting Nurse Service of Greater Rhode Island have been successful twice, in the first case restoring her speech and in the second her ability to walk. After the home visit where we accompanied nurse Linda McCormick, I had the honor of conducting an in-depth interview with Governor Carcieri. In this candid exchange, the governor spoke passionately about his crusade to protect the right of aged, ill and disabled citizens to remain in their homes and receive necessary health care services there.

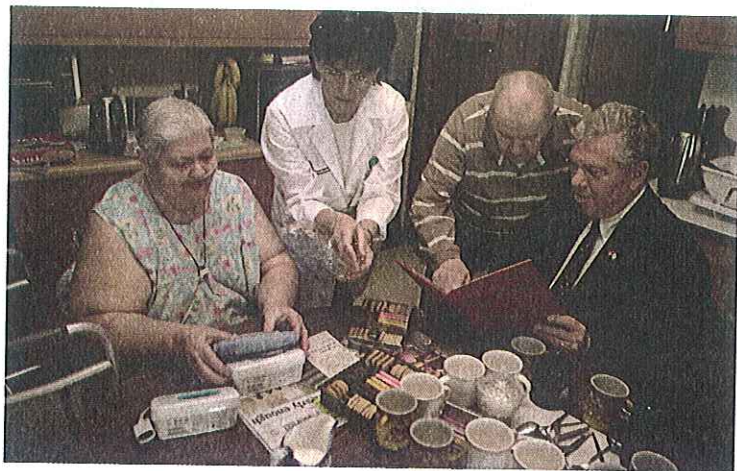
Among his many important points, Governor Carcieri also took sharp exception with proposals from the Office of Management and Budget, which are pending in Congress and would cut \$13 billion over the next five years from the \$16 billion Medicare home care benefit. "Don't cut home care because you are just going to push the system back to an institutional bias, and that is exactly the wrong thing to be doing right now. What we have got to do is find out how to build more robust support for home care."

Richard Brennan (RB): Thank you Governor for taking the time to go out on this home care visit and for doing this interview. Did you enjoy the visit?

Gov. Donald Carcieri (DC): Yes, Concetta Ball seemed to be in exactly the sort of situation we've talked about. She's mobile. She's alert. She needs oxygen. And she'd like to be at home versus being in a nursing home. This is precisely the kind of activity that I support and would like to see more of.

Rich Brennan (RB): So let's start with the Balls since we just came from their house, where Concetta told us her story. She said she had a couple of strokes, had to learn to speak again, and couldn't remember her children's names. But she was able to recover at home with her husband, Frank, because of the support she got from the home health care workers.

DC: It was astounding, wasn't it? It really was amazing when she described having had the two strokes. I said, "You don't appear to have had any significant impact from that," though normally you get slurring and problems in the arms and legs. She said she had lost her speech, but she got it back fine. And then, if you noticed, she was able to use her right side, so she's just recovered beautifully. There's no question in my mind that being in her own home with her husband—that being in a comfortable environment one that she knows—has to have



Above (top picture) Concetta Ball and Linda McCormick use a remote monitoring device while Frank Ball shares his yearbook with Gov. Carcieri; and (bottom picture) Gov. Carcieri's home care visit provided a unique opportunity for the Ball's to emphasize the importance of medical care that is delivered in their home.

assisted her in bringing back those faculties. I think that's exactly what our Medicaid waiver is going to accomplish by encouraging more use of home care. It's better for the individual, as you can tell from talking to Concetta.

She made it pretty clear that she has no interest in going to a nursing home, and she doesn't need a nursing home. She doesn't need that level of intensity, and she's thriving much better in her home environment.

RB: *What's so extraordinary about home care is how it builds on the strong foundation of the family structure. Frank, her husband, really plays a key role in keeping her home, but there's no way they could do it on their own. There's a unique fit here.*

DC: Yes. I think that was pretty obvious from the relationship the nurses have with Concetta. They understand what she needs and when they need to come in. Frank is there to help out and do the things that any spouse would do to be accommodating, but he's not medically trained and certain things he can't do. It's also clear, since they've been married for 54 years, that his presence nourishes her and helps her recover from the stroke. She's much happier being cared for at home. And it's better from Frank's standpoint, too. I know this from having been through family situations where someone has gone into a long-term nursing facility.

It's really tough for the spouse because they're used to being with someone. Now they're alone; now they've got to go to the nursing home to visit their partner. That's not as easy as it sounds. It's an emotional kind of thing for a spouse who's still at home to see their loved one be in this environment. They feel kind of powerless to help.

RB: *You have done a great job and have been hitting on the strengths of providing medical care in the home. The ones that I like to point too are that it helps families stay together, it's cost-effective, and it improves the patient's quality of life. Maybe you could talk about the greatest benefit of home care to your state.*

DC: Well, we need to do more of all the things you just mentioned. I think the data is clear. Seniors do much better if they're in a comfortable environment like their own home. They eat better and they don't fall as much. The incidence of hospitalization and the need to go to the emergency room are very much reduced. The outcomes, in terms of the whole impact on the system, are much better, too, when seniors know where the doors are, where the light switches are, where the walls are, and where the counters are so they can lean on them when they want. The data on the benefits of home care is overwhelming, so I want to see more of this happening in our state.

What's happened over the years is that people who have been well off have been able to finance that kind

of care for themselves. But people who are dependent or aren't eligible for Medicaid haven't had that right. This is the whole point of our global waiver. You get the advantages of better outcomes and lower costs because it's actually less expensive in the long term to keep people in their homes. You make this accessible to a broader range of our population through Medicaid. And that's exactly what we're trying to accomplish with our Medicaid waiver.

RB: What reforms are you considering that would be of interest to home care and hospice community?

DC: Well, exactly what we're talking about today. Because right now if you look at the percentages spent on long term care, Rhode Island spends 60 percent on Medicaid long-term care money and on placing people in nursing homes one of the highest in the country.

If you look at Vermont, another New England state, it's the opposite ratio. I think their percentage spent on nursing homes, is less than 20 percent. So, what I'm trying to do with the waiver is move our system of care away from an institutional bias.

We have an older population in Rhode Island and we're not alone. The demographic bubble in this country soon is going to burst. I'm on the leading edge of the Baby

Boom Generation. I was born in 1942. The population of the country, like our state, is aging. Soon there's going to be more need for support, so we need to begin offering options and choices, like Concetta and Frank have: to stay in the home, or maybe even in assisted living or some kind of shared living arrangement for those whose spouse is deceased. For example, there are individual families who are willing to take in a senior and have them live with them if there's a way to defray the cost.

There are a whole series of options that we want to make available. We want to make them available. We've got to develop that capacity right now. By the way, nursing homes do a great job – this is not a criticism of nursing homes. But not everybody needs to be there, and not everyone requires the intensive level of medical care that a nursing home provides. So what we're trying to do, Rich, is develop all those different options, and staying at home is the preferred one.

RB: What's so extraordinary is that I heard you saying home care has been an option for people who could pay for it out of pocket. But the Medicaid population, like you said, has had to put up with institutions and their vices.

Nobody wants to be totally dependent or helpless, and few seniors want to be placed in an institution unless they need



Concetta Ball stands to greet Gov. Carcieri and thank him for his visit to her Providence, Rhode Island home.

24-hour care. Would you agree that home care is a viable solution and a way to keep this care in the community?

DC: Absolutely. Home care is our key first line of defense because there is no question in my mind that people are going from their homes into nursing homes, even though they don't need to. It is because they don't have any support. There isn't a good structure in place.

Obviously the home nurses are doing a great job. In Frank and Concetta's case, there is a home health aide coming in as well, and they said that Meals on Wheels is delivering a hot meal at noon.

As we saw, all you need the pieces in place, and clearly that is where we should be going on because home care is really the best. It is what virtually everyone I know wants. I've seen it in my own family, and I see it in my friends; people want to stay in their homes especially in their twilight years. We have to find ways to make people as comfortable as possible, as long as possible, in their own homes.

RB: Thank you for your comments so far. I want to make sure that we also touch on hospice. What are some of the benefits that you're looking for in hospice?

DC: I would make two points. First of all, hospice care is wonderful.

In my case, my mother, in the last few days of her life was in a nursing home as a self-pay. My dad, a teacher, had died and left her alone. But hospice came, and they were fantastic. The family was all there, and it was wonderful how they dealt with us and helped us understand what was happening. I remember very clearly how they said, "Your mom knows you're here, and she's okay."

Hospice is a great concept with great people. Our state pays for hospice services. Anyone who has had experience with hospice cannot say enough good things about it. Hospice is an important part of the health care delivery system. At the end of the day, we are all going to pass on. For the family as well as the individual, that final time period is very tough. So having trained people who've been through this and understand what the family, as well as the patient, are going through is just a wonderful, wonderful service.

RB: I want to get your reaction to the subject of pending cuts. Medicaid represents the single largest expense in states. It averages about 25 percent of each state's budget. Congress has been asked to cut about 13 billion dollars from the \$16 billion federal Medicare Home Health Benefit. That would mean an additional one to three million acutely-ill Americans would come off the Medicare enrollment, and increase Medicaid's portion of each state's budget by about one third or more. I wanted to ask if you would be willing to stand with other governors to oppose cuts in the federal Medicare home health program?

DC: Yes, absolutely. I think that is the wrong way to go. One of the things we are trying to accomplish with our waiver is to develop enough options and put more resources into home care. It is better for the individual, produces better outcomes, and is actually a more efficient thing to do. I think that if the Administration does its homework and talks to people like we've done today – it will realize that is the wrong way to go. What we have got to do is find out how to build more robust support for home care.

I'm from a generation when doctors used to make house calls. I'm 66 and home care is what we did. It's



Gov. Carcieri gives Rich Brennan a tour of his office at the Rhode Island State House after the conclusion of their interview; a special thank you to the VNS of Greater Rhode Island and to Gov. Carcieri and his staff for making this home visit and interview possible.

what people did 100 years ago, when they stayed in their homes and the doctors came to them. Now we've got different technologies and everything's changed. But with home care, I think we're just going back to the future, back to where it should be, as long as it can be.

So, I would be supporting those governors and those senators and representatives who say, "No, that's not the direction to go." We've got to shift the system away from the institutional bias, and the way you do that is to support home care. Don't cut home care since you're just going to push the system back to the institutional bias. And that's exactly the wrong thing to be doing right now.

RB: *I want to get your reaction to a question about chronic health conditions. Chronic health conditions consume about 78 percent of U.S. health care spending. They encompass 95 percent of Medicare spending, and 77 percent of Medicaid spending. Leading efforts to prevent and manage chronic diseases and injuries among seniors include a combination of health promotion and health care interventions. What successful strategies are you identifying to better manage, minimize, and prevent the impact of chronic illness in your state?*

DC: One of the major drivers we've had in our state is wellness. First of all, we all need to take more responsibility for our own health. But like anything else, we also need direction and support to do it. This means a whole series of things, including smoking cessation, weight management, and diabetes, which is an especially big problem. Both Frank and Concetta are diabetic. I have it in my family, and all the data is crystal clear.

It says you have to keep a stricter and stricter watch over your blood sugar. Well, that takes help. It takes monitoring. But the difference in outcomes is significant. When you trace most chronic diseases and most costs in the health care system, you see they're the product of poor management in terms of weight, cholesterol, smoking, and diabetes.

To a large degree of us what is producing rising costs in the health care system. Listen, cancer will happen, occasional people get hit by a car – those things are just going to happen. But analysis of the cost of health care shows that much of it is driven by chronic conditions which you can control and delay to avoid their impact through disease management, or their onset with wellness programs.

We kicked off several programs becoming the first "well" state in the nation two years ago. What that meant is that the state's large employers offered wellness programs to their employees. We made a real push and received an award for our achievement.

Tied onto that, I think the insurance system needs to incentivize people to take better care of their health. One of the things we did this past year for our own state workers was to give them up to \$500 off their share of the health care premium if they do a few things – fill out a health assessment form, go see their primary care physician at least once a year, enroll in weight management programs, and so on down the list. If you do these things, you get \$500 off your health care premium.

Our insurers need to embed these kinds of incentives more in the whole system, and we need to do a better job of encouraging people to take charge of their own health. They're going to be better off, living richer and healthier lives. They'll also delay the onset of diseases that we know will occur without proper management and control.

RB: You just highlighted one of the key strengths of home care. It's that nurses are out in the community, and can help in the effort of educating people about proper nutrition and how to take care of themselves. They can be used as a valuable tool in that way.

DC: Yes. Clearly, monitoring blood pressure is very important. Now I know from experience with my own family, that you have to check your blood sugar probably four or five times a day. The home health care nurses can go in there and say, "Have you checked your blood pressure?" Maybe she has, maybe she hasn't. Check it again. "What was your last blood sugar test?" So you're absolutely right, Rich. That's the point of having a home health care system with nurses and aides visit patients homes. They can ask the right questions, and get people back on track if they're slacking off.

RB: Let me add something about the ways our industry is leading the way in managing chronic illness. We're combining the strengths and educational resources of home care with advanced communication technologies, such as the home monitoring device that we saw at the Balls. Instead of seeing somebody once or twice a week and getting a diagnosis from an RN, we're monitoring them 24 hours a day.

If there's a significant change for the worse, the nurse tracking the data from the home monitoring can talk about it to a physician and find out if they need to change their medication. So is your state planning to invest in the future of health care by encouraging health information technology?

DC: Yes. Again, we're leading the way. In terms of health information technology, there are a couple of fronts that relate to what you are describing. Where Rhode Island varies from Massachusetts is on e-prescribing. We're number one versus their being number two in getting all physicians to write prescriptions electronically. Right now, we're one of the leaders in terms of building an electronic health exchange that makes people's health information available both to them and to all providers. This matters because one of the things we've found out is that a lot of costs in the system occur when physicians don't have the information before them about our health and our health needs.

There is technology being developed right now, coming back to diabetes, that automatically sends the results of a blood sugar test to your medical records or your doctor. You can set up parameters to fine tune the process. Let's say you're expecting two or three tests a day, and the test hasn't come in today; you can set up procedures for

calling back and saying, "Concetta, we haven't seen your blood sugar today." Or if the data is showing that the blood sugar is a little high, you go back to Concetta and say, "Are you eating too many sweets? Are you not getting enough insulin? And do we need to adjust it?"

Technology, as far as I'm concerned, is the key to the whole health care system and making it more cost-effective. You do that by getting information. Nurses and home health aides play a crucial role because they're there and can make sure the information is flowing. That's been at the top of our agenda since I became governor. We're pushing electronic health information as a way to give better care and get better care.

It's also a way to be more efficient over the long term because providers will have the information in front of them immediately to help them make good decisions.

RB: Thanks for pushing through a raise for skilled nursing services and for home care aides. It will help because we're dealing with a shortage of skilled nurses and aides. It would also be wonderful if we could make it possible for all governors and elected officials to have come with us and visit Frank and Concetta today. Our home visit to the Balls, shows the important role that home care plays in keeping Concetta in her home where she wants to be.

DC: Yes. I think our visit today was very important in the context of the policy issues we've been talking about. You're reminded of home care's benefits when you see Concetta and Frank in their home, learn what she had to deal with after having two strokes, and hear about how she responded with the help she has had from home health nurses and aides. All this crystallizes beautifully what we've been discussing and why home health care is so very important.

RB: Thank you for your time.

DC: You're welcome.



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